

Longitudinal Changes in Family Outcomes of Very Low Birth Weight

Melisa Moore,¹ MA, H. Gerry Taylor,² PhD, Nancy Klein,³ PhD, Nori Minich,² BS, and Maureen Hack,² MBChB

¹Department of Psychology, Case Western Reserve University, ²Department of Pediatrics, Case Western Reserve University and Rainbow Babies & Children's Hospital, University Hospitals of Cleveland, and ³Department of Education, Cleveland State University

Objectives Although children with very low birth weight (VLBW, <1500 g) are at high risk for developmental impairments, we know little about the long-term effects of VLBW on families. This study examined long-term family outcomes and their stability over time. **Methods** Participants were the families of 64 children with <750 g birth weight, 54 with 750–1499 g birth weight, and 66 term-born controls. Family burden and parental distress were assessed annually as part of longitudinal follow-up of the children from mean ages 11–14 years. **Results** Family burden and parental distress were higher in the <750 g group than in the term-born group, but differences varied with the child's age and family environment. **Conclusions** The findings document long-term effects of VLBW on families that are moderated by the degree of low birth weight, child's age, and family environment.

Key words family outcomes; low birth weight; longitudinal change.

Survival of children with very low birth weight (VLBW, <1500 g) has increased dramatically over the past decade (Fanaroff, Hack, & Walsh, 2003). Compared with term-born controls, however, these children are at increased risk for deficits in global cognitive functioning, academic achievement, and behavior (Taylor, Klein, Minich, & Hack, 2000). Children with VLBW are also more likely than term-born children to have weaknesses in attention and executive functions, perceptual motor ability, memory, and math skills—weaknesses that cannot be fully explained by low IQ and neurosensory deficits (Klein, Hack, & Breslau, 1989; Szatmari, Saigal, Rosenbaum, & Campbell, 1993; Taylor, Burant, Holding, Klein, & Hack, 2002; Taylor, Hack, Klein, & Schatschneider, 1995; Taylor, Klein, Minich, & Hack, 2000). Cognitive and behavioral deficits are found in both preschool and school-age children; and school-age children with VLBW have higher rates of grade repetition and special education than term-born controls (Taylor et al., 2000). Research on

adolescent outcomes of VLBW suggests that sequelae persist over time (Saigal, Hoult, Streiner, Stoskopf, & Rosenbaum, 2000).

Outcomes of VLBW vary in relation to biological and social risk factors. Sequelae are more pronounced in children with lower birth weight, indicating a gradient effect (Breslau, Chilcoat, Del Dotto, Andreski, & Brown, 1996; Horwood, Mogridge, & Darlow, 1998; Klebanov, Brooks-Gunn, & McCormick, 1994; Taylor, Minich, Klein, & Hack, 2004). Additional predictors of poor outcome include neonatal complications, such as chronic lung disease and cerebral abnormalities on cranial ultrasonography (Frisk & Whyte, 1994; Landry, Chapieski, Fletcher, & Denson, 1988; Taylor et al., 1998), and disadvantaged family environments as defined by low socioeconomic status (SES), family stressors, or lack of family resources (Bendersky & Lewis, 1994; Taylor et al., 1998; Taylor et al., 2004).

All correspondence concerning this article should be addressed to H. Gerry Taylor, PhD, Department of Pediatrics, Rainbow Babies & Children's Hospital, 11100 Euclid Avenue, Cleveland, Ohio 44106-6038. E-mail: hudson.taylor@case.edu.

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VLBW also has adverse effects on families. In a study by Cronin, Shapiro, Casiro, and Cheang (1995), parents of young children with VLBW reported more financial, social, and family stress than parents of control children. In one of the few longitudinal studies of family outcomes, Singer et al. (1999) showed that adverse family consequences of VLBW persist over the first 3 years of life, at least for higher risk children with chronic lung disease.

The findings from two studies indicate that family sequelae persist into the school-age years. Saigal, Burrows, Stoskopf, Rosenbaum and Streiner (2000) administered a family survey to two groups of parents, one with adolescents with <1000 g birth weight and the other with adolescents of normal birth weight. The survey was designed to assess employment, marital and family-related issues, as well as attitudes about the treatment of children with low birth weight. Parents in the <1000 g birthweight group reported that their children brought the family closer together. However, these parents also reported more marital stresses and strains, more negative effects of children's health problems on siblings and their own emotional health, and more concern that they were paying less attention to siblings than did parents of term controls.

In a second school-age follow-up of children with VLBW, our research team examined family outcomes in children with VLBW at mean age 11 years as part of a larger longitudinal project (Taylor, Klein, Minich, & Hack, 2001). The sample included two groups of children with VLBW, one with <750 g birth weight and one with 750–1499 g birth weight. Each of these groups was compared with a term-born control group. Family outcomes were assessed in terms of parent reports of family burden, parental psychological distress, parenting stress, and family functioning. Group comparisons indicated poorer family outcomes in the <750 g group than in the controls. Specifically, the former group reported lower perceptions of parenting competence, more difficulties in child attachment, and more child-related family burden. Based on findings from parent interviews, the sources of family burden included concerns about the child's self-esteem, acceptance by peers, and future, as well as burden related to the need for child supervision and altered family routines. Group differences in family outcomes were not found when the children's neurosensory status and behavior problems were taken into account, suggesting that the neurobehavioral effects of VLBW on the children contributed to negative family effects.

Further study is required to examine potential changes in family effects as children grow older and to

determine whether these effects are moderated by family characteristics. Families of children with severe traumatic brain injury (TBI) experience higher burden than families of children with other injuries (Wade et al., in press; Wade et al., 2002). The family burden of severe TBI persists for years after injury, with greatest burden in families with many stressors and few resources. Given that severe TBI and VLBW both result in chronic child behavior problems, and assuming that these problems contribute to family burden (Taylor, Klein et al., 2001; Taylor, Yeates et al., 2001), one would anticipate similar findings in follow-up studies of children with VLBW.

In this study, we extended our initial investigation of family outcomes (Taylor, Klein et al., 2001) by examining family consequences of VLBW across four follow-up assessments. The family follow-ups were included as part of annual assessments of the children conducted from mean ages 11–14 years. Our major goal was to investigate changes in family effects across the follow-up period and to explore moderating influences of the family environment on these effects. Following recommendations to assess multiple domains of family outcome, we measured both parent perceptions of child-related burden on the family and clinically relevant symptoms of parental distress (Wade, Drotar, Taylor, & Stancin, 1995). In view of findings showing that VLBW has long-term consequences on children's development, we hypothesized that adverse family outcomes of VLBW would also persist over the follow-up period. Given results from our previous study (Taylor et al., 2001), we expected to find more evidence of family adversity in the <750 g group than in the lower risk, 750–1499 g group. Based on related research on outcomes of TBI in children, we additionally predicted that more advantaged family environments would attenuate adverse family consequences of VLBW.

Method

Sample Recruitment and Follow-Up

The sample included children and caregivers who were recruited for a study of early school-age outcomes of extremely low birth weight (Hack et al., 1994) and who subsequently participated in a longitudinal follow-up. The initial sample comprised the 68 children with <750 g birth weight, 65 children with 750–1499 g birth weight, and 61 term-born controls. Children in the <750 g group were 93% of the survivors of <750 g birth weight born at neonatal intensive care units in our region from July, 1982 through December, 1986. The 750–1499 g group consisted of next-born children from

the same hospitals as children in the <750 g group and of the same sex and race. The term-born control group included children who were from the same schools as children in the <750 g group and of the same sex, race, and birth date within 6 months.

The follow-up phase of the study began approximately 4 years after initial recruitment and involved four assessments spaced at yearly intervals. The follow-up sample included those participants who remained in the study, together with an additional child with <750 g birth weight who had not taken part in the initial assessment. We also recruited term-born “replacements” for term-born children who had dropped out after the initial assessment ($n = 11$) and to fill previously unfilled control slots ($n = 6$). One hundred and eighty-four families participated in these follow-up assessments, including 64 in the <750 g group, 54 in the 750–1499 g group, and 66 in the term group.

Due to attrition, the follow-up sample diminished to 133 families (66% of original sample) by the final follow-up. Forty-four of these families were in <750 g group, 42 were in 750–1499 g group, and 47 were in the term group. Attrition occurred in a graduated fashion across assessments, with 180 families (90% of the sample) remaining at the age 11 assessment, 155 at the age 12 assessment (77%), and 143 at the age 13 assessment (71%). To assess attrition bias, we compared the children who had dropped out by the end of follow-up to the original sample in terms of background characteristics. Results failed to reveal differences between the final sample and the families who dropped out in the distributions of children by group, sex, or racial/ethnic background. However, children who dropped out had lower SES than children who completed the study.

Procedures and Measures

Overview

Institutional review board approval and informed parental consent and child assent were obtained before participation; although only measures administered to parents were examined in this study (custodial caregivers were considered as parents). The vast majority of respondents (88%) were mothers, with the remaining informants being fathers (4%) and grandparents (8%). The groups did not differ significantly with regard to the type of respondent. Family outcomes were assessed through interviews and questionnaires administered to parents while the children were being tested. Only data from the same caregiver were considered in the analysis.

Measures of Family Outcomes

Family outcomes were assessed using two self-report scales for parents: the Family Burden Interview (FBI;

Taylor, Klein et al., 2001) to assess child-related family burden, and the Brief Symptom Inventory (BSI; Derogatis & Spencer, 1982) to assess parental psychological distress. In conducting the FBI, developed specifically for this study, parents were first queried as to whether their children had any medical, developmental-learning, school, or emotional-behavioral problems. For identified problems, parents were then asked about the nature of their concerns for the child and family. Parents rated each concern, or burden, on a 0–4 scale from not stressful to extremely stressful. The measure of child-related family burden used in analyses was the natural log of the number of items rated as stressful (out of 19 possible). Log transformation was used to normalize the distribution. We also identified families with burden versus no burden. Families with “some burden” were defined as those that rated at least one of the FBI items as stressful.

The validity of the FBI was demonstrated by its sensitivity to the effects of VLBW in our previous study of family outcomes (Taylor et al., 2002) and by its correlation with the negative impact score of the Impact of Family Scale (Stein & Jessop, 1985), an alternative measure of child-related family burden administered at the age 11 assessment, $r = .58$, $p < .01$. Test-retest reliability was demonstrated by a moderate to high intra-class correlation of the FBI total score across the first two follow-up assessments, $r = .68$, $p < .01$. Alpha coefficients for the total sample across the four assessments ranged from .91 to .94 (all $ps < .01$), indicating good internal reliability. The validity of dividing families into those with some versus no burden was supported by significant point biserial correlation between the presence of some burden and the Impact on Family Scale negative impact score ($p < .01$).

The BSI is a widely-used 53-item self report questionnaire designed to tap a broad range of symptoms of psychiatric distress. The measure yields three global indices and nine subscale scores. Internal consistency for the subscales ranges from .71 to .85 as reported in the manual and .63 to .83 in our sample at mean age 11. Test-retest reliabilities for the global scales range from .87 to .90. Validity has been demonstrated by correlations of scores with other measures of psychiatric symptoms. The Global Severity Index *T* score (GSI) was used in this study as a summary of parental distress. To identify parents with high distress, we used an established cutoff as defined by a GSI >63 on the BSI or a *T* score >63 on at least two subscales of the BSI (Derogatis & Spencer, 1982).

Measures of the Family Environment

Three measures of the family environment were also assessed to investigate social predictors of family outcome and to determine whether the family environment

moderated the effects of birth weight on family outcome. The distal family environment, or SES, was defined by the Four Factor Index (Hollingshead, 1975) and the proximal environment by parent responses to the Life Stressors and Social Resources Inventory, Adult Form (LISRES-A; Moos & Moos, 1994). The LISRES-A is a questionnaire designed to assess health-related stressors, negative and positive life events, and interpersonal conflicts and supports. It has documented internal consistency, temporal stability, and validity in predicting adult psychopathology. For the purposes of this study, a stressors score was defined as the mean of the *T* scores for six stressors scales (Health, Work, Spouse, Extended Family, Friends, and Negative Life Events), and a resources score as the mean of the *T* scores for five resources scales (Work, Spouse, Extended Family, Friends, and Positive Life Events). These measures of the family environment were assumed to reflect ambient family characteristics potentially related to the family outcomes by virtue of influences outside the child. Although it is possible that the child had some indirect effect on the family environment (e.g., by contributing to conflicts between the parent and others or by limiting opportunities for the parent to seek higher education or better employment opportunities), direct influences of the child on SES and family stressors and resources were considered unlikely, particularly as the child scales of the LISRES-A were excluded from consideration in forming the composite stressors and resources scores.

Data Analysis

Linear mixed model analysis was used to examine changes with the age of the child in the FBI and BSI (Burchinal, 1999). This method of analysis is a sensitive way to assess change over time, and it allows parameter estimation of correlations across multiple assessments. This method also permits unequal spacing of assessments and considers incomplete longitudinal data. A further advantage is that factors that change over time, such as the family environment, can be taken into account as time-varying covariates to assess the concurrent effects of these factors. These analyses were conducted using SAS Proc Mixed (Singer, 1998).

In this study, age and age² were treated as random factors to account for the linear and quadratic effects of age. In evaluating age-related change in family outcomes, the combined effect of both factors was tested (i.e., age + age²). Fixed factors were birth weight group, sex, and race. Time-varying predictors were SES and family stressors and resources. Group differences in change over time were explored by including interactions of group with the age factors; and moderating effects of the family factors were examined by including interactions

of these factors with group. Triple interactions of group with the age and family factors were also considered. To identify the most parsimonious models, initial models were trimmed by eliminating nonsignificant interaction terms. To examine the effects of the three family factors in a manner that preserved statistical power, we first considered only SES and interactions with this factor. After trimming, we entered stressors and its interactions. We then examined the effects of resources and its interactions in a similar manner. Main effects for group, sex, race, and SES were included in all models. Effects of stressors and resources were retained only if these factors or their interactions predicted family outcomes. Secondary analyses were also conducted in which the effects of multiple births, major disability, and asthma were added one-by-one to the final models for the FBI and BSI.

Group differences in the rates, or odds, of the two dichotomous measures of family outcome (some versus no child-related burden on the FBI, and high parental distress on the BSI) were analyzed using SAS GENMOD for general estimating equation. (GEE) (Diggle, Liang, & Zeger, 1994). The GEE method, which has similar advantages to that of mixed model methods in analysis of repeated measures data, provided tests of group differences in the covariate-adjusted proportions of adverse outcomes. The factors included in the GEE models, and the model fitting procedures were the same as those employed in the mixed model analyses. The GEE method was also employed to examine group differences in rates of burden on individual items of the FBI, the purpose of these analyses being to explore the nature of group differences in total burden.

Because the study was exploratory and employed only two primary measures of family outcome, statistical significance was defined by a *p*-level <.05. Effect sizes for group differences on the continuous family measure were defined in terms of the difference in the expected values of the least-squares estimates for each group divided by the between-subjects standard deviation (*SD*) of that estimate, as computed from the mixed model analysis. This definition is analogous to Cohen's *d* (Cohen, 1988) and represents the difference between groups in *SD* units. The magnitude of group differences obtained from GEE analysis was provided by the odds ratio (OR) and 95% confidence interval (CI).

Results

Sample Characteristics

Table I summarizes group characteristics at the first follow-up assessment. The mean ages of each group at the four follow-up assessments are also presented. Despite

Table I. Sample Characteristics for Follow-up Study

Variable	Group		
	<750 g (N = 64)	750–1499 g (N = 54)	Term (N = 66)
Males [n (%)]	20 (31)	17 (31)	22 (33)
Minority race [n (%)] ^a	30 (47)	28 (52)	33 (50)
Single-parent households [n (%)]	21 (33)	24 (44)	22 (33)
Mean (SD) Hollingshead Four Factor Index	36.5 (12.7)	33.8 (14.2)	35.7 (13.1)
Mean (SD) birth order	1.8 (1.3)	1.8 (0.9)	1.9 (1.2)
Mean (SD) number of children in family	2.5 (1.5)	2.5 (1.0)	2.8 (1.5)
Mean ages in years (SD)			
First follow-up assessment ^b	11.3 (1.5)	11.0 (1.2)	11.3 (1.3)
Second follow-up assessment	12.3 (1.2)	12.3 (1.4)	12.2 (1.1)
Third follow-up assessment	13.1 (1.1)	13.2 (1.2)	13.2 (1.1)
Fourth follow-up assessment	14.1 (1.1)	14.0 (1.1)	14.1 (1.1)
Mean (SD) maternal age at birth in years	25.8 (5.6)	25.0 (5.5)	25.7 (5.0)
Mean (SD) birth weight in grams**	668 (67)	1179 (215)	3342 (586)
Mean (SD) gestational age in weeks**	26 (2)	29 (2)	Unknown
Mean (SD) length of hospitalization in days**	129 (74)	62 (50)	Unknown
Multiple births [n (%)]**	6 (9)	9 (17)	0 (0)
Neurosensory disorders [n (%)]** ^c	10 (16)	4 (7)	0 (0)
Major disability [n (%)]** ^d	27 (42)	9 (17)	6 (9)
Asthma [n (%)]*	11 (17)	15 (28)	5 (8)

^aAll children of minority race were African American and three were of Hispanic ethnicity.

^bAlthough family data were available for 184 participants at some point during the follow-up interval, only 180 completed the family measures at the first follow-up.

^cThe 10 children in the <750 g group with neurosensory impairments included five with cerebral palsy, two with hearing impairment, and four with visual impairment. The four children in the 750–1499 g group with these impairments comprised three with cerebral palsy and two with hearing impairment.

^dA major disability was defined by the presence of a neurosensory disorder or a prorated IQ <70 on intelligence testing as described in the *Methods*.

According to post-hoc tests using the Tukey method, all three groups differed in birth weight. Pairwise comparisons of groups using χ^2 revealed higher rates of multiple births and neurosensory disorders in both low birthweight groups than in term group, higher rates of major disability in the <750 g group than in both other groups, and higher rates of asthma in the 750–1499 g group than in the term group.

* $p < .05$. ** $p < .01$.

the anticipated differences in birth weight, gestational age, and length of neonatal hospitalization, the groups were similar in sex and race distribution, as well as in mean SES and mean age at each follow-up. Group comparisons also failed to reveal differences in the proportions of one- versus two-parent households, mother's age at the child's birth, birth order, or number of children in the family, but did reveal a slightly higher proportion of primary caretakers in the VLBW groups who were grandparents or adoptive or foster parents (17% of both VLBW groups versus 3 % of term group), $\chi^2(2, N = 184) = 7.80$, $p < .05$. The groups also differed in rates of multiple births, neurosensory disorders as defined by the presence of cerebral palsy or a vision or hearing disorder, major disabilities as defined by a sensorineural disorder or IQ <70 (see measures), and asthma, a common health problem in survivors of VLBW (Hack, Klein, & Taylor, 1995).

Descriptive Data

Table II summarizes unadjusted group means and SDs across follow-up for the two family measures. This table

also provides the frequencies across follow-up of families reporting any stress on the FBI and of parents endorsing high levels of distress on the BSI. These data provide description information on scores and on the number of observations considered in estimating group differences.

Mixed Model Analysis of Family Outcomes

Mixed model analysis of burden on the FBI family measures revealed a significant main effect for family stressors, $F(1, 248) = 14.22$, $p < .01$, and a triple interaction of group \times age + age² \times family resources, $F(4, 248) = 2.62$, $p < .05$. Higher family stressors predicted higher FBI scores. To aid in interpretation of the triple interaction, Fig. 1a and b graph estimated mean burden scores across follow-up as indexed by the child's age. Figure 1a presents the group by age interaction for families with low resources (one SD below the sample mean), and Fig. 1b presents the same interaction for families with high resources (1 SD above the sample mean).

Simple effects testing of mean differences in burden for families with low resources (Fig. 1a) revealed higher

Table II. Descriptive Data Across the Follow-Up Assessments for the Family Burden Interview (FBI) and Brief Symptom Inventory (BSI)

Measure	Follow-up assessment ^a			
	1	2	3	4
Stresses endorsed on FBI (out of 19), mean (n, SD) ^b				
<750 g group	4.53 (61, 5.32)	4.85 (52, 5.20)	4.61 (48, 5.43)	3.79 (44, 5.05)
750–1499 g group	2.53 (51, 3.29)	3.13 (47, 4.21)	2.15 (42, 3.63)	2.51 (42, 4.10)
Term group	3.14 (60, 4.72)	2.10 (54, 3.84)	1.64 (50, 3.51)	2.19 (47, 4.13)
Families reporting any stress on FBI (%)				
<750 g group	38 (62)	34 (65)	31 (65)	23 (52)
750–1499 g group	26 (51)	21 (45)	18 (43)	19 (45)
Term group	31 (52)	18 (33)	13 (26)	13 (28)
BSI General Severity Index T score, Mean (n, SD)				
<750 g group	51.08 (62, 9.34)	50.35 (52, 10.29)	50.30 (47, 11.45)	48.66 (44, 9.68)
750–1499 g group	51.88 (52, 8.74)	50.43 (47, 9.78)	49.21 (42, 8.08)	47.33 (42, 9.16)
Term group	51.37 (65, 10.74)	49.50 (54, 10.89)	47.82 (50, 11.41)	48.96 (47, 11.96)
Parents reporting high distress on the BSI (%) ^c				
<750 g group	18 (29)	13 (25)	15 (32)	7 (16)
750–1499 g group	14 (27)	10 (21)	9 (21)	7 (17)
Term group	18 (28)	11 (20)	12 (24)	12 (26)

^aMean ages at follow-up assessments 1, 2, 3, and 4, respectively, were 11, 12, 13, and 14 years.

^bThe log of FBI Stresses was used in mixed model analysis of this measure.

^cHigh parental distress was defined as a BSI General Severity Index >63 or at least 2 subscale scores >63.

means for the <750 g group than for the term group at ages 11 and 12 only. Respective effect sizes for these differences were .52 and .47. Similar tests for families with high resources (Fig. 1b) indicated higher means for the <750 g group than for term controls at each age, as well as a higher mean for the 750–1499 g group than for controls at age 14. Respective effects sizes for the <750 versus term comparisons at age 11, 12, 13, and 14 were .51, .64, .71, and .71; and the effect size for the 750–1499 g versus term comparison was .40. We thus interpret the interaction effect as evidence that the higher parent burden in the <750 g group was less persistent for families with low resources than for families with high resources. The findings additionally indicate late emergence of burden for the parents of children with 750–1499 g birth weight with high resources. Follow-up comparisons for families at low and high resources failed to reveal significant group differences in change across follow-up.

Analysis of the BSI indicated significant effects for stressors, $F(1, 115) = 106.90, p < .01$, and the triple interaction of group, age + age², and SES, $F(4, 115) = 3.18, p < .05$. Higher stressors predicted higher BSI scores. The triple interaction is displayed in Fig. 2a and b. These two figures show the group by age interaction for families with low SES (1 SD below the sample mean) and high SES (1 SD above the sample mean), respectively.

Simple effects testing of mean differences for families with low SES (Fig. 2a) revealed higher means for the <750 g group than for the term group at ages 11 and 12

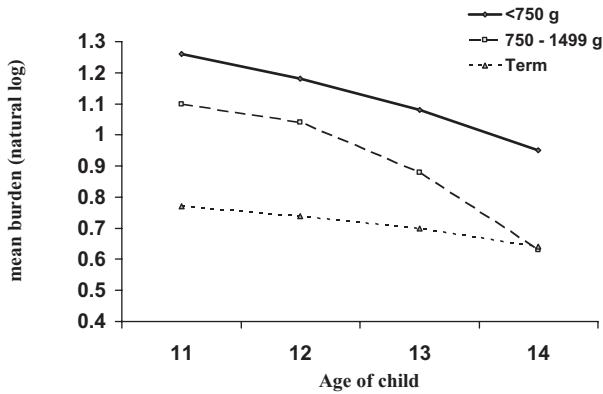
only. Respective effect sizes for these differences were .71 and .56. No group differences were found for families at high SES (Fig. 2b). We thus interpret the triple interaction as evidence for greater parental distress in the <750 g group compared with term controls, but only early in follow-up for families with low SES. Follow-up tests failed to indicate group differences in change over follow-up for families with low SES, but did reveal an interaction of group with the age + age² factor for families with high SES. Simple effects indicated a steeper decline in parental distress in the term group than in the VLBW groups. Although this finding is difficult to interpret in light of the lack of significant group differences later in follow-up, it is consistent with the results from analysis of the FBI in suggesting more persistent family adversity for socially advantaged children with VLBW.

Results from the primary analyses were not altered substantially by inclusion of multiple births, major disabilities, or asthma to the models. Although none of these factors predicted the BSI, family burden was higher for children with a major disability, $F(1, 248) = 20.40, p < .01$.

GEE Analysis of Rates of Adverse Family Outcomes

Consistent with the results of mixed model analysis, GEE analysis revealed higher frequencies of any burden in the <750 g group than in controls (Table III), OR (CI) = 2.99 (1.64–5.46), $p < .01$. Analysis of rates of high

(a) Low Family Resources



(b) High Family Resources

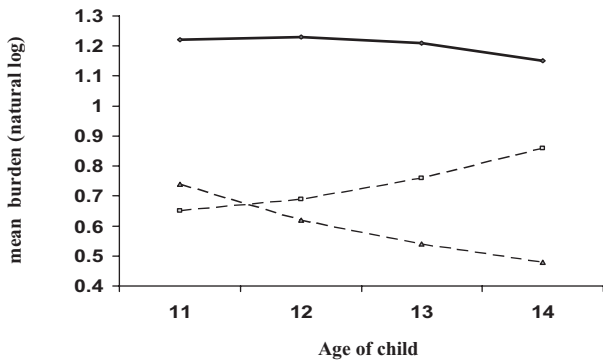
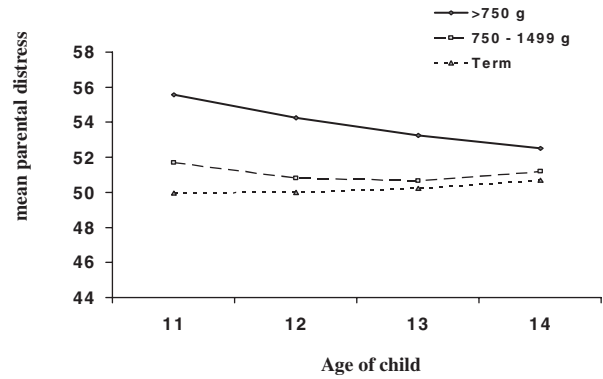


Figure 1. Model estimates of group means across follow-up in the natural log of the number of burdens (i.e., ratings of child-related stress) endorsed on the Family Burden Interview (FBI). The number of items endorsed was prorated in cases of items that were inapplicable to a given family (e.g., items pertaining to spouses or siblings in single-parent families in which the participating child had no siblings). The means graphed in Fig. 1a and b are model estimates at low and high levels of family resources, as defined by values 1 SD below and above the sample mean, respectively. At a low level of resources (i.e., relative environmental disadvantage), burden was significantly higher for the <750 g group than for the term group at ages 11 and 12. At a high level of resources (i.e., relative environmental advantage), burden was significantly higher for the <750 g group than for the term group at all ages, and significantly higher for the 750–1499 g group than for the term group at age 14.

parental distress on the BSI revealed results similar to those from the mixed model analysis of this measure, with significant effects for stressors, $\chi^2(1, N = 184) = 41.47, p < .01$, and a triple interaction of group \times age \times SES, $\chi^2(1, N = 184) = 7.00, p < .05$. Follow-up tests to determine the source of the interaction indicated higher rates of adverse outcomes in the <750 g group than in controls, but only early in follow-up (ages 11 and 12) for families with low SES (1 SD below the sample mean).

(a) Low SES



(b) High SES

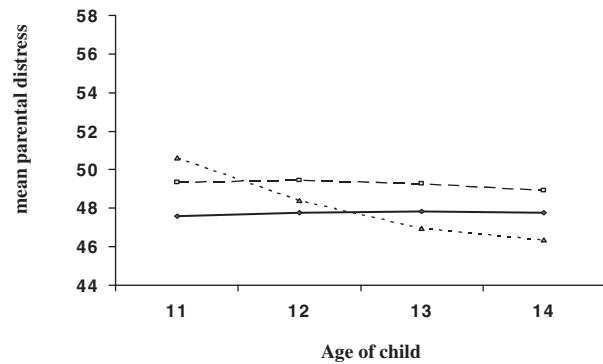


Figure 2. Model estimates of group means across follow-up in parental distress, as assessed by the Brief Symptom Inventory (BSI) General Severity Index T score. The means graphed in Fig. 2a and b are model estimates at low and high levels of socioeconomic status (SES) as measured by the Hollingshead Four Factor Index and as defined by values 1 SD below and above the sample mean, respectively. At a low level of SES (i.e., relative environmental disadvantage), parental distress was significantly higher for the <750 g group than for the term group at ages 11 and 12. Group differences were nonsignificant at a high level of SES (i.e., relative environmental advantage).

Adjusted proportions of families reporting parent distress in the <750 g and term groups were .42 and .13, respectively, at age 11 (OR = 4.93, CI = 1.56–15.59, $p < .01$), and .35 and .16 at age 12 (OR = 2.70, CI = 1.02–7.15, $p < .05$).

Rates of burden on the FBI were higher in the <750 g group than in controls for FBI items pertaining to the child's acceptance by peers, OR (CI) = 4.28 (1.84–9.91), $p < .01$; getting along with other children, OR (CI) = 2.30 (1.08–4.90), $p < .01$; need for child supervision, OR (CI) = 3.44 (1.82–6.50), $p < .01$; self esteem, OR (CI) = 3.39 (1.71–6.74), $p < .01$; child's future, OR (CI) = 2.67 (1.46–4.89), $p < .01$; family routines, OR (CI) = 2.72 (1.31–5.66), $p < .01$; time the family spends together,

Table III. Group Differences in Rates of Adverse Family Outcomes or Reported in Family Burden Interview (FBI)

Outcome measure	Adjusted proportions (standard errors) by group		
	<750 g	750–1499 g	Term
Frequency with which stress endorsed on at least one item**	.62 (.06)	.46 (.06)	.35 (.05)
Frequency of “yes” responses to individual items:			
1. Difficult for you to manage this problem?	.27 (.05)	.16 (.03)	.18 (.04)
2. Acceptance by peers**	.28 (.05)	.12 (.03)	.08 (.03)
3. Gets along with other children?***	.21 (.04)	.12 (.03)	.11 (.03)
4. More dependence/need for supervision?***	.43 (.05)	.24 (.05)	.18 (.04)
5. Is self-esteem lower?***	.35 (.05)	.24 (.05)	.14 (.03)
6. Concerned will effect the child’s future?***	.50 (.06)	.37 (.06)	.27 (.05)
7. Difficulties in school meeting needs?	.15 (.04)	.14 (.03)	.09 (.03)
8. Resources (besides school) to meet needs?	.09 (.02)	.05 (.02)	.07 (.02)
9. Difficult for you to accept/deal with problem?	.24 (.05)	.14 (.03)	.17 (.04)
10. Concerns about spouse accepting/dealing with problem?	.14 (.04)	.11 (.04)	.06 (.03)
11. Concerns about siblings accepting/dealing with problem?	.20 (.05)	.15 (.04)	.11 (.03)
12. Concerns about other family members accepting/dealing with problem?	.16 (.04)	.07 (.03)	.07 (.03)
13. Problem affected family routines?***	.22 (.04)	.12 (.04)	.09 (.03)
14. Problem affected your work or education?	.16 (.04)	.13 (.04)	.08 (.03)
15. Difficult to spend time with other children?	.12 (.03)	.05 (.02)	.06 (.03)
16. Difficult to spend time with spouse?	.06 (.02)	.03 (.02)	.02 (.02)
17. Difficult for family to spend time together?*	.11 (.04)	.02 (.01)	.05 (.02)
18. Problem affected family finances?*	.13 (.04)	.08 (.03)	.04 (.02)
19. Uncomfortable around others?	.13 (.03)	.08 (.02)	.06 (.02)

The data presented in this table are from general estimating equation. (GEE) analysis of dichotomous (yes/no) data. Group proportions are estimated for children at age 12 and are adjusted for gender, race, socioeconomic status (SES) as measured by the Hollingshead Four Factor Index, and the stressors score from the Life Stressors and Social Resources Inventory – Adult form.

*Difference between <750 g and term groups significant, $p < .05$.

**Difference between <750 g and term groups significant, $p < .01$.

OR (CI) = 2.65 (1.06–6.59), $p < .05$; and family finances, OR (CI) = 3.39 (1.24–9.31), $p < .05$. The group differences did not vary by age and were not moderated by family factors.

Discussion

These findings revealed more long-term burden and parental psychological distress for families of children with VLBW than for families of term-born children. However, the adverse effects of VLBW differed somewhat for the two measures of family outcome used in this study and varied according to the degree of low birth weight, family characteristics, and the child’s age. As evident in Fig. 1, child-related family burden on the FBI was higher in the <750 g group than in term-born children at ages 11 and 12 years. Similar differences were observed at ages 13 and 14 years, but only for high-resource families. Burden for high-resource families was also higher in the 750–1499 g group than in the term-born group, but this difference was evident only at the final follow-up. As seen in Fig. 2, a somewhat different pattern of findings emerged in examining parent self-reports of

psychological distress using the BSI. On this measure, as on the FBI, parents of children in the <750 g group fared less well than parents of the term-born group at ages 11 and 12 years. In contrast to the results for the FBI, however, these differences were found only when family SES was low and were not observed in any subset of families later in follow-up.

The fact that adverse family consequences of VLBW were more evident for the <750 g group than for the 750–1499 g group is consistent with our previous results (Taylor et al., 2002). This finding suggests that children at higher medical risk present greater challenges to families. These challenges may relate to prenatal risk factors (e.g., poor maternal health) that increase likelihood both of low birth weight and of postnatal family outcomes, to prolonged disturbances in parent–child relationships secondary to longer periods of neonatal hospitalization, or to difficulties managing the adverse effects of high-risk birth. The latter interpretation may be the most tenable in light of the well-established associations of VLBW with child cognitive and behavior outcomes (Botting, Powls, Cooke, & Marlow, 1997; Horwood et al., 1998), and of child behavior and health

problems with family difficulties (Cronin et al., 1995; McCain, 1990; McCormick, Stemmler, Bernbaum, & Farran, 1986; Taylor, Klein et al., 2001; Thompson et al., 1993). In support of this interpretation, findings from our previous study indicated that children's neurobehavioral functioning mediated the family consequences of extreme low birth weight (Taylor et al., 2002). We did not investigate mediation in this study, but did observe more negative family outcomes for children with major disability. Inclusion of the disability factor in the analytic model did not alter group effects; hence, family adversity may also be related to more subtle behavior or learning sequelae in children without major disability.

Although we hypothesized that group differences in family outcomes would be moderated by family characteristics, the results only partially confirmed our initial expectations in this regard. According to research on the family consequences of childhood TBI and of child behavior and developmental disorders, negative family consequences are exacerbated by environmental disadvantage (Keogh, Garnier, Bernheimer, & Gallimore., 2000; Wade et al., 2004; Wade, Taylor, Drotar, Stancin, & Yeates, 1996). The finding that differences between the <750 g group and controls in parental distress were limited to lower SES families is consistent with this literature. In keeping with models of risk and resilience (Wallander et al., 1989), this finding suggests that less advantaged families are more negatively affected by their children's problems, perhaps due to the presence of other stressors in their lives or lack of supports to help them manage or provide respite from these problems.

However, the fact that higher burden in the <750 g group persisted across follow-up only for families with higher resources cannot be explained on this basis. The different pattern of outcomes for the FBI and BSI likely reflects differences in the constructs assessed by these two measures. The FBI assesses perceptions of child-related burden, whereas the BSI involves self-ratings of psychological distress. Distress is not source specific and cannot be attributed solely to parenting difficulties. Perceptions of burden, on the other hand, signify only parent concern about the child and may not be accompanied by parent adjustment problems. Restriction of group differences on the FBI at the later follow-ups to high-resource families may thus indicate a greater sensitivity in these families to the child's problems. Parents with high resources may have been less overwhelmed by other concerns and more cognizant of their children's problems or of the impact of these problems on the family than parents with low resources.

The presence of this moderating effect only at the final two follow-ups, in turn, may be explained by decreases with age in children's dependence on their parents, resulting in burden below the level of awareness of parents from low-resource families. Alternatively, parent-child interactions or involvement in children's activities may decrease with age more rapidly in lower resource families, making child problems less burdensome to these parents. Findings in support of the latter possibility include observations that parent-adolescent conflict lessens with advancing age and that adolescents from disadvantaged environments are more willing to make concessions to their parents than those from advantaged environments (Laursen, Coy, & Collins, 1998; Smetana & Gaines, 1999).

Greater family burden in the 750–1499 g group than in the term-born group at the final follow-up, at least in high-resource families, may also be due to heightened parental sensitivity to child problems or limitations. Although we can only speculate, children in the 750–1499 g group from high-resource families may reach at point at which they have more difficulty coping with social or cognitive demands, or at which parents are less able to help them cope with these demands. Whatever the reasons for this age-specific finding, the elevated family burden that was evident across follow-up in the <750 g group was present in both VLBW groups at this last follow-up.

Analysis of rates of burden on the FBI confirmed the clinical significance of findings from the mixed model analyses. Parents of children in the <750 g group reported higher rates of at least some burden on the FBI than did parents of term-born children. Findings from analysis of individual FBI items documented specific parental concerns related to both the child (i.e., need for supervision, peer relationships, self-esteem, future) and the child's effect on the family (i.e., family time together and finances). Based on adjusted proportions, parents of the <750 g group were nearly twice as likely as parents of control children to endorse some form of child-related burden, with similar group differences evident for several of the individual FBI items (Table III).

Also in parallel with the mixed model results, the <750 g group had higher rates of clinically significant levels of parental distress than the control group, though these differences were again found only in association with low SES and only at the first two follow-ups. In terms of adjusted proportions, high parental distress was three times more common in the <750 g group than in the control group at age 11 years, and twice as common in <750 g group at age 12 years. The results additionally

demonstrated that, although family burden and parental distress were endorsed by a substantial percentage of parents in the <750 g group, negative family outcomes as assessed by the FBI and BSI were by no means universal. Many parents of children in the <750 g group failed to endorse either burden or parental distress (e.g., 29% at the age 12 assessment).

One of the unique features of the study was the repeated assessment of family burden and parental distress to examine stability and change in family outcomes. To our knowledge, this is the first study to assess longitudinal changes in family consequences of VLBW during the later school-age years or to consider moderating influences of the family environment. Further strengths include the recruitment of a regional sample of children with <750 g birth weight and use of statistical methods appropriate for studies of longitudinal change (Burchinal, 1999).

One of the study's weaknesses was the attrition that occurred over the course of follow-up, with disproportional attrition in lower SES families. Although SES was taken into account in the analysis and the absent follow-up data would thus be considered "ignorable missing" (Schafer, 1997), caution is advised in generalizing these findings to a broader population of children with VLBW. Increased attrition over time, for example, may have introduced imprecision in estimates of the moderating effects of SES on group differences across follow-up in the BSI. Also, both predictors and outcomes were assessed via interview with the same parent, thus shared method variance was a limitation. Additional weaknesses include lack of information on family outcomes earlier in development, the restricted range of outcome measures, and the relatively small sample size. Some family effects may not have been detectable given our sample size, especially among families with children in the lower risk 750–1499 g group. Finally, results from the FBI pertaining to specific areas of burden are considered preliminary due to the multiple comparisons involved in conducting these analyses.

Despite these limitations, this study has several clinical and research implications. With regard to research initiatives, evidence for long-term family consequences reinforces the need to examine family outcomes more systematically. This findings indicate that family outcomes are likely to vary across different family measures and to change with the child's age, substantiating the importance of longitudinal studies of multiple family outcomes. The findings also suggest that effects on families will depend on the extent of biological risk (as indexed in this study by birth weight) and on characteristics of the family environment. Failure to consider

these factors may either obscure the effects of VLBW on families or make it difficult to understand the family processes that contribute to these effects. The complicated pattern of group differences emerging from this study was unanticipated.

The post-hoc explanations offered to account for many of the results make it difficult to draw firm conclusions, and replication is required to substantiate the findings. Nevertheless, the complexity of the results underscores the importance of evaluating family outcomes within both a developmental and family context. Similar considerations may well apply in studies of the family consequences of other at-risk populations, such as children at-risk for neurological insults and those with chronic illness or disability (Drotar, 1997; Wade et al., 2004). Additional research is needed to evaluate the effects of VLBW on a broader array of family outcomes, including interactions between family members, parental monitoring of the child, and parenting style (Montemayor, 1986). It will also be important to study the persistence of family consequences into later adolescence, the child characteristics that contribute to family burden, and the ways in which the families adapt to this burden. Examination of family outcomes within a broader causal framework is indicated to take into account the influences of prenatal family risks, the family's response to the child's initial medical status and extended hospitalization, the child's developmental status, and family supports or stressors that may buffer or exacerbate negative family consequences of VLBW.

With respect to clinical practice, the findings support the need to assess family functioning in children with VLBW throughout the school-age years and to develop interventions for both the child and family. Targeting of families of children with extremely low birth weight and consideration of parent perceptions of child-related burden as well as parental psychological distress are especially critical. Discussion of the specific areas of burden identified on the FBI may be useful in surveying parent concerns. These findings also raise the possibility that burden may vary with family characteristics; and that parents from more disadvantaged backgrounds may be more vulnerable to psychological distress. Research is additionally needed to investigate approaches to family intervention and to explore methods of providing effective family support and counseling.

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